Parenting with Disabilities

Berkeley Planning Associates for
RTC on Families of Adults with Disabilities
at Through the Looking Glass

The following findings of the RTC National Survey of Parents with Disabilities, conducted by Berkeley Planning Associates, are reprinted by permission of Berkeley Planning Associates and the RTC on Families of Adults with Disabilities at Through the Looking Glass. The purpose of this survey, which interviewed 1175 respondents, was to identify service needs, current service system options, gaps and problems in service delivery, and possible solutions to the unique problems faced by parents who have disabilities. However, for the purposes of this issue of DSQ, these results provide a description of parents with disabilities and examples of some of the problems they encounter. For a complete copy of the report, please use the address at the end of the article.

The survey was supplemented by secondary analysis of the 1993 Survey of Income and Program Participation (SIPP) conducted by the U.S. Census Bureau to: (a) estimate the prevalence of disabled parents among different populations of adults with disabilities; (b) examine how disabled parents compare with other disabled adults and other parents; and (c) examine the extent to which our sample is representative of the national population of disabled parents.

Who are Disabled Parents?

Analysis of the 1993 SIPP census data reveals that close to one-third of disabled women and a quarter of disabled men are parents. Compared to other disabled adults, disabled parents are more likely to have attended college and to be working. They also tend to have correspondingly higher household incomes than other disabled adults, although their average income is substantially lower than that of non-disabled parents.

On average about 30% of disabled adults are parents, compared to 40% of non-disabled adults. However, the proportion of disabled adults who are parents varies significantly across disability groups. Adults with sensory disabilities are just as likely to be parents as non-disabled adults, but parenting is less frequent among adults with other types of disabilities, especially among adults with cognitive disabilities.

Analysis of the characteristics of respondents to the RTC survey revealed that: Nine out of ten respondents are white, three-fourths are women between the ages of 30 and 59, the average age of the sample is 44.

Two-thirds of respondents are either married or living with a partner. More women are single parents (over one-third) than men (one out of five).

Almost one-quarter of respondents live with a partner who also has a disability. Just over one-quarter have at least one child who is also disabled.

Like non-disabled parents, respondents have an average of two children. Over 80% of the respondents' children are biological children, 10% are adopted and 8% are step children.

Overall, four out of five respondents have a physical disability. While some may have more than one type of disability, for 70 % of the sample, the primary disability is physical. Over one-quarter of the total sample has a sensory disability, one in five has a cognitive disability, one in seven has a psychiatric disability and 4% have an "other" disability (e.g., AD/HD, Tourette Syndrome, substance abuse).

Nearly one-quarter of the parents were disabled at birth, and the average age of onset for those who became disabled later is 24. Almost half of the sample became disabled before the age of 18. Half of all respondents report that their disability is episodic or progressive.

The disabled parents responding to the survey tend to be highly educated: about half have either a college or a graduate degree. Individuals with psychiatric disabilities have the lowest education level while those with "other" disabilities have the highest education level.

Almost half the sample is currently employed and another 8% are seeking work. Men are more likely to be employed than women as are individuals with stable conditions as compared to episodic or progressive conditions. Forty-two percent of households have a combined incomes of less than $30,000 while 22% have combined incomes over $75,000.

How Generalizable Are the Survey Results to the Nation as a Whole?

Our survey sample is similar to disabled parents in the nationally representative SIPP census data in terms of employment status, distribution of disability type, and marital status. However our sample differs from the national population in that it includes fewer minorities, more women, and generally higher income and education levels than the national population. Even though the survey sample is highly educated and on average earning more than parents with disabilities nationally, the large majority of respondents receive at least one form of public assistance benefits.

Also, specific disability groups are under-represented within the broader disability types including parents who are deaf, or who have mental retardation or a psychiatric disability. These differences are consistent with the types of self-selection bias that one would expect on a written survey, even with accom-

modations provided such as the toll free phone number with TDD. Our sample reflects well known trends in survey research such as the fact that women are generally more likely to respond to surveys about parenting issues than men, adults with higher income and education levels are more likely to respond to surveys in general, fewer minorities typically participate in any type of survey research, and the under represented disability groups are those that are typically less likely to respond to disability surveys. Despite targeted outreach efforts, it is important to take these differences into account when interpreting the findings of the survey.

Given the somewhat smaller representation among the survey of families with racial and economic barriers, we would anticipate that the challenges, barriers and service needs we present here are somewhat under reported, with even greater proportions of disabled parents likely to report these as issues if more parents with low income, low educational levels, and members of ethnic minority groups had participated.

Major Challenges to Parenting with a Disability

Survey respondents answered questions about a variety of potential challenges to parenting with a disability:

The top three areas where disability creates challenges are employment and recreation (each reported by three-fourths of the sample) and transportation/ community access (reported by three out of five respondents). These are followed by emotional aspects of parenting, physically caring for children and romantic relationships (all of which are reported as problems by the majority of respondents).

Transportation issues cut across all other issues examined in the study, from child care to recreation to housing. Four out of five respondents report transportation as an issue on at least one item on the survey. A major transportation problem reported by disabled parents is that paratransit services do not allow or are not suited to traveling with children.

Almost half of respondents report that they (or their partner) experienced problems during pregnancy and birthing due to their disability. Lack of disability expertise among providers and attitudinal problems are more frequently cited as issues than medical complications due to disability or physical or communication access problems.

Of those who report needing some kind of adaptive parenting equipment, almost half (48%) report that cost is the biggest barrier to obtaining this equipment, and 44% report lack of information is the greatest barrier. Fewer than one-third of the sample uses adaptive parenting equipment.

More than 40% of disabled parents report having difficulty finding ap-

propriate housing for raising their families. More parents report difficulty finding housing that is suitable for children than report problems finding housing that is physically accessible.

Almost half of all survey respondents identify at least one barrier to obtaining child care. Cost is the most commonly identified barrier.

Four out of five respondents report that they need some kind of personal assistance services (PAS). Over half of disabled parents use personal assistance for parenting tasks. Yet those who rely on government sponsored personal assistance are typically not allowed to use that help for parenting instead of personal care.

Among disabled parents who use help with parenting tasks, most rely on family and friends for help. Those who do use personal assistants to help with parenting report that assistants are often unreliable and lacking in knowledge about caring for children.

Two out of five respondents report having faced attitudinal barriers as disabled parents. About one-third of all respondents report that they have been discriminated against as a parent.

The High Costs of Parenting with a Disability

At the same time as disabled parents often have additional expenses above and beyond those typically associated with raising a family, they also tend to have lower income than other families. Employment is the most frequently cited area in which disability presents a barrier. Even so, most of the families who participated in our survey have at least one parent working. Even though our sample included a larger proportion of middle and higher income families than typical disabled parents nationally, limited financial resources are still frequently cited as a barrier to effective parenting. In fact the majority of disabled parents rely on some form of public assistance. In spite of their limited resources, many families stretch their income to cover additional expenses because there are limited subsidies available, and there is no organized delivery system to help parents access the types of assistance that are available.

Survey results show that cost is the greatest barrier to parents having the housing, personal assistance, child care and adaptive parenting equipment they need. These findings confirm the common knowledge in the disability community that having a substantial disability can significantly increase the costs associated with parenting and raising a family. Cost was raised as an issue of concern throughout the survey. There are a number of areas in which parents report expenses that are specifically related to parenting with a disability and that contribute to a higher cost of living than that experienced by parents without disabilities. Some examples include:

1. Housing modifications - Most parents report making some type of modifications to their homes either to make family housing accessible to accommodate their disability, or to make accessible housing suitable to accommodate raising children. Housing modifications range from relatively low cost solutions such as installing new hardware on cupboards and doors or installing visual alarms, to much more expensive modifications such as modifying bathrooms, widening doorways or adding rooms.

2. Transportation - While some disabled parents use regular public transportation (one in eight among those with physical disabilities and one-third of those with non-physical disabilities), most disabled parents use their own vehicle for transportation. Disabled parents report that paratransit services (transportation services designed specifically to serve people with disabilities) often do not allow or are not suited to traveling with children. Those parents with disabilities who do use paratransit services may also incur additional cost, as many paratransit programs cost more than the regular bus service. For those who need modifications to their vehicles (e.g., hand controls for cars or accessible vans) these also represent additional costs. A few parents even need to rely on paid help to drive them for errands and appointments, sometimes in addition to the cost of a lift equipped van that they can get in and out of. These additional costs are compounded by the fact that parents with disabilities often have more errands and appointments than non-disabled parents, including medical and therapy appointments as well as appointments with various service agencies.

3. Child Care and Parenting Assistance - Over half of disabled parents report needing assistance in caring for their children due to their disability. Only 10% of those who need parenting assistance get financial assistance to pay for it, so most parents rely on unpaid help from family or friends and/or have to pay for it themselves. Disabled parents also report barriers to accessing child care services, including both accessibility and financial barriers. Limited choices of child care options available to them increases their need to rely on family and friends to help them in caring for their children.

4. Adaptive Parenting Equipment - Although most parents responding to our survey report never having used adaptive parenting equipment, the majority report that adaptive parenting equipment could have helped them. Among those who do use adaptive parenting equipment, almost all pay for it themselves, and the inability to pay for it was given as one of the major reasons that parents don't have the equipment they need. Adapted baby carriers and backpacks, changing tables, cribs and strollers are among the most common types of adaptive parenting equipment that parents have used, generally designed by the parents themselves.

Service Providers Lack Awareness That Many Parents Have Disabilities

Many of the responses to the RTC survey suggest that many of the barriers parents with disabilities encounter reflect a lack of awareness among policy-makers and service providers of the fact that adults with substantial disabilities are often also

parents. It often seems as if neither policy makers or service providers can visualize disabled people as parents, what their needs might be, or how existing services should be modified. This lack of awareness can effectively exclude people with disabilities from services in a variety of ways, and is evident in this sample of survey responses that indicate barriers such as:

Medical care providers are not trained to provide services to individuals with disabilities who want to become parents and in some cases, actively discourage them from becoming parents. Lack of disability expertise and attitudinal problems among service providers during pregnancy and birthing are reported by parents as greater challenges than physical barriers.

Given that there is no standardized definition or assessment of parenting competence, social workers and the legal system can easily discriminate against disabled parents in custody battles through lack of knowledge, or by assuming disabled parents are less capable of raising their children than non-disabled parents or even other relatives.

Not only do providers of services to the general population seem unaware of disabled parents and their needs, but even services that specifically target people with disabilities seem unaware that many of their constituents have children. As was evident during our efforts to distribute the survey, most disability service organizations have not yet begun to consider the needs of their clients who are raising families. As we recruited disability organizations to help us publicize and distribute the survey, we were continually surprised at how often disability advocates and agency representatives either misunderstood our intent (thinking we were looking for parents of children with disabilities), or acknowledged that this was a population they had not yet begun to address.

Responses to the RTC survey highlighted a number of areas where this lack of awareness has translated into barriers for disabled parents. For example, survey respondents report that accessible housing is not designed to accommodate children. Housing that is designed specifically to accommodate parents with disabilities lacks sufficient rooms and outdoor play areas, and is not conveniently located near parks, schools or day care. Respondents also report that accessible transportation, especially paratransit, is not designed to accommodate children. For example, accessible transportation typically lacks children's restraint systems and regular seating sufficiently near the wheelchair seating space.

Survey responses suggest that disabled parents often experience a lack of flexibility in program policies as a barrier to getting the help they need with raising their family in the best way that works for them. For example, many need the flexibility to use personal assistance resources in the way that they feel is best for their family. Whether that involves using personal assistance to provide personal care for the parent, assist with parenting activities or do housekeeping chores, is a

choice that is probably best made by the parents themselves rather than dictated by guidelines developed with apparent lack of awareness that service users are often parents. If the personal assistant is already preparing dinner or doing other household chores for the parent, why not for the child also? Personal assistance service definitions need to be expanded to include assistance with parenting activities as an Activity of Daily Living - not as an extra but as an integral part of community living.

On the other hand, survey responses suggest that the assistants that provide personal care for parents may not be best suited to providing parenting assistance unless they are familiar with caring for children, are available when needed, reliable, and can help without interfering with the parent's own role. Many of the parents surveyed do not find that their personal assistants meet these criteria.

Implications of the Survey Findings

The survey findings presented here represent a first look at a myriad of complex issues that are heavily loaded with societal values and norms. As we explore the interrelationships between some of these issues, such as the role of personal assistants, attitudinal barriers and occasional outright denial of an adult's right to be a parent, we see that by failing to acknowledge that many parents are disabled our society and service delivery systems not only fail to provide support that parents need, but actually create substantial barriers that make raising a family more difficult. Both for disabled people who choose to have families and for parents who become disabled, there are a number of public policy changes that are needed before parents with disabilities can focus their energies on their families, instead of on advocacy or removing barriers.

In its most benign form, lack of awareness of the existence of parents with disabilities results in both mainstream and disability service systems overlooking the needs of disabled parents. At its worst, this lack of awareness is accompanied by prejudice and structural barriers that make the task of raising children even more challenging than it already is.

As people with disabilities become more interwoven into the fabric of society through community integration and increased self-determination, it is only natural that more will take on family roles. The public policy context in which this occurs can have a major impact on the success of the parenting experience, especially among parents with the most severe disabilities. Whether through benign neglect or outright discrimination, survey findings suggest that both mainstream and disability-specific service systems need significant improvements both to accommodate individuals with disabilities who choose to become parents, and to minimize the challenges faced by parents who become disabled.

While it was not possible to structure a nationally representative sample of parents with disabilities for the RTC survey, the survey provides a great deal of valuable information about challenges faced by parents with disabilities and public policy changes that can begin to address those challenges. Underlying all of these issues are some basic philosophical questions about the rights of disabled adults to raise children, the extent to which society should support those rights if parents need help in raising their children or are unable to support their families financially.

Policies and procedures of both mainstream and disability-specific programs need to be reviewed to ensure that parents with disabilities are neither neglected nor systematically excluded. In many cases significant changes can be made within existing programs simply through increasing awareness about parents with disabilities. In other cases structural changes are needed.

The full 200 page report is available at a cost of $25.00 (including postage and handling) from: Linda Toms Barker, Berkeley Planning Associates, 440 Grand Avenue, Suite 500, Oakland, CA 94610; FAX - 510-465-7885, Phone - 510-465-7884, TDD - 510-465-4493.